

End of Life Care Strategy

2013 – 2017



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Foreword

The North East Essex end of life service is for adults aged 18 years and over who;

- have an advanced progressive or incurable condition and are expected to die within the following 12 months.
- are at risk from dying from a sudden acute crisis in their condition.
- have a life threatening acute condition caused by sudden catastrophic events

The service offers support to the families and carers during the end of life pathway and a bereavement service after death.

End of life care for children and young adults is not included in this strategy as the model of care within this document is specific to adults and does not address the specific needs of children and young adults and their families and carers.

This strategy was developed in collaboration with the North East Essex End of Life Project Board which includes representation from independent providers and primary and secondary care providers. The strategy is evidenced-based and draws on national as well as local evidence and best practice, including the recommendations of the recent Keogh Review which considered end of life provision across the health economy and made particular recommendations on improving the pathway.

Purpose of this strategy –

- Commissioning end of life care pathways that are what patients want, clinically effective, financially sustainable and holistic.
- Embed the principles of the national strategy
- Further address the NHS Improving Quality remit
- Address the gaps of the current system locally, as identified by the Keogh Review (July 2013), and the North East Essex Clinical Commissioning Group End of Life Review in August 2013

This strategy builds upon the large amount of work that has already been undertaken over the previous 5 years for example; introducing a 24 hour single point of access called 'SinglePoint', extended hours for clinical response teams and establishing an economy wide real time palliative care database and website 'My Care Choices'.

These developments have been implemented under transformation funding with local providers working in partnership. Patient engagement has been key in these developments and actively participated in throughout the various stages. In addition, resources have also been directed towards primary care through a Local Enhanced Scheme to cascade end of life training to clinicians in general practices, increase the frequency of multidisciplinary meetings, increase the identification of patients nearing the end of life and offer them informed choices, and work towards meeting their wishes. In acute care, work has been undertaken to improve end of life communications within the organisation and with community end of life teams through CQUIN and clinical agreements.

This strategy document is in support of and supported by other local organisational strategies, namely;

North East Essex Integrated Plan 2013 – 2018

North East Essex Clinical Commissioning Group Governance Assurance Framework

North East Essex Clinical Commissioning Group Quality Strategy 2013 - 2018

Executive Summary

This document is a 5 year strategy detailing the future commissioning of end of life services across the health and social care economy. The document identifies the importance of raising the profile of achieving 'a good death' and putting mechanisms in place to achieve this.

The Department of Health End of Life Care Strategy acknowledges that there are many challenges to be overcome to ensure that everyone attains 'a 'good death' irrespective of their background. The focus for the North East Essex Clinical Commissioning Group End of Life Strategy is to ensure that all patients achieve 'a good death' and their families and carers feel supported.

The Joint Strategic Needs Assessment (JSNA) for north east Essex, identifies that people are living longer and the majority of people at end of life are elderly. Forecast increases in population size, in particular the over 75 years age group, will put a strain on the health and social care economy unless improvements in the current service provision are identified with focussed investment to support these improvements.

National guidance (DoH) identifying best models of care as well as recommendations from local reviews (Keogh, JSNA) have been used to inform the model of care within this strategy that will be commissioned. The local engagement exercise, 'The Big Care Debate' has highlighted that single point access to services and providers working together are the most important factors for our local population. The commissioning intentions are detailed within the strategy with an overall focus on empowering the patients and their families to identify their end of life care preferences and how this is then communicated and co-ordinated across the economy. Models of care such as the Gold Standard Framework and the Amber Care Bundle will be implemented to assure the quality of care provided across multiple providers.

The focus will be an integrated approach, co-ordinated through a single point of access and determined by the end of life register and advance care planning. The elements of the model to be commissioned include;

- End of life register
- Advance Care Planning
- Single Point of Access
- Key workers/care co-ordinators
- Rapid response
- Specialist Nursing and community teams
- Improving Access to Psychological Therapies
- Hospice Care
- Transport
- Social care

There is a high prevalence of undiagnosed dementia across north east Essex and people with dementia who are dying should have the same access to end of life care services as those without dementia. The Care Closer to Home Strategy will commission services to improve early diagnosis and care for people with dementia, and this strategy identifies action across the economy to support end of life planning for patients, their family and carers and the health and social care workers providing care and support specific to the needs of people with dementia.

We face extremely challenging times in the NHS. Demand for services is rising faster than our funding. The costs of drugs and new medical technology continue to rise. Our population is

changing, with an increasing number of older people, who tend to have greater health and social care needs.

The size of the financial challenge is derived from the difference between the resource allocation we receive as an organisation and the anticipated expenditure required to meet the growing healthcare needs of our population. Over the next 3 years the productivity challenge will be between £45m (best case scenario) and £98m (worst case scenario), dependant on the impact of changes in funding allocations and decision mechanisms centrally.

Until now, although the NHS has certainly faced challenges, they have not been of this scale.

In previous years the strategic commissioning of services has focussed around service lines and organisations and not around the component packages of care that individuals require. In moving forward to address this mismatch between commissioning and need, efficiencies will need to be identified within the system to fund new ways of working. The end of life model of care within this strategy focusses on investing the knowledge and skills into the community and provider services, working jointly with voluntary sector organisations to provide the best quality, clinically safe service for people and their families within the community setting. People nearing the end of life should not have to be admitted to the acute providers as a default position due to the lack of experience and/or co-ordination in the community and primary care sectors.

Having the right support and services within the community will give the patients and their families the confidence to remain at home and experience a 'good death'. These services can only be developed with the input from patients, families and carers.

1 Background

In 2008 the national End of Life Strategy¹ identified the need for commissioners and providers to work together across the acute and community settings to ensure that people with advanced, progressive and incurable illness were given the opportunity to live as well as possible. It promoted people dying at home as a preference to dying in hospital, with the palliative care team providing support to the patient and their families; all of which required collaborative working and good planning to make this possible. The National Audit Office in 2008² estimated that 40% of the patients who had died in hospital had not had medical needs, and were inappropriately placed in the acute setting as a default position resulting from the lack of a better supported option for patients.

In 2010 Kings Fund³ identified that people are living longer but with increasingly complex health problems; this together with the need to take account of patient preferences, highlights the importance of developing the appropriate models locally for end of life care and the increasing investment that will be required in this area of care. The report goes on to say that many organisations continue to struggle with implementing the national End of Life Strategy in relation to developing innovative models of care focussed around individual patient needs within increasing financial constraints.

The five year End of Life National Programme work came to a close in March 2013, however not all recommendations had been fully embedded across the country and as a result the NHS Improving Quality Team are now leading the work to;

- Transform end of life care in acute hospitals
- Implement electronic palliative care co-ordination systems
- Establish healthcare facilitators and social care champions networks

The Keogh Review into the quality of care and treatment provided by Colchester Hospital University Foundation Trust (CHUFT) identified the need for further joint working across the economy to find solutions for patients who could appropriately be at home, or in their normal place of residence to receive end of life care. The report stated that systems currently in place were too complex with limited joined up working, flagging end of life provision across the economy as a key risk.

The review found that the Summary Level Hospital Mortality Index (SHMI) at CHUFT was higher than expected and concluded that this was in part a consequence of the lack of genuine choice and support for patients and their families in identifying their preferred place of care.

A baseline audit was carried out locally⁴ by 39 practices, 38 of whom have signed the Local Enhanced Service (LES). The audit covered all deaths over the age of 65 in 2012/13. The practices recorded 2774 deaths, of which 35% (964) were on the register before death. Of these, 56% (539) had a Preferred Place of Care (PPC) recorded, and of these, 87% (470) died in their PPC. However, the aggregate proportion of all deaths of people who were on the register with a specified PPC and died, was 17%. This demonstrates that once patients have made their choices, community teams are

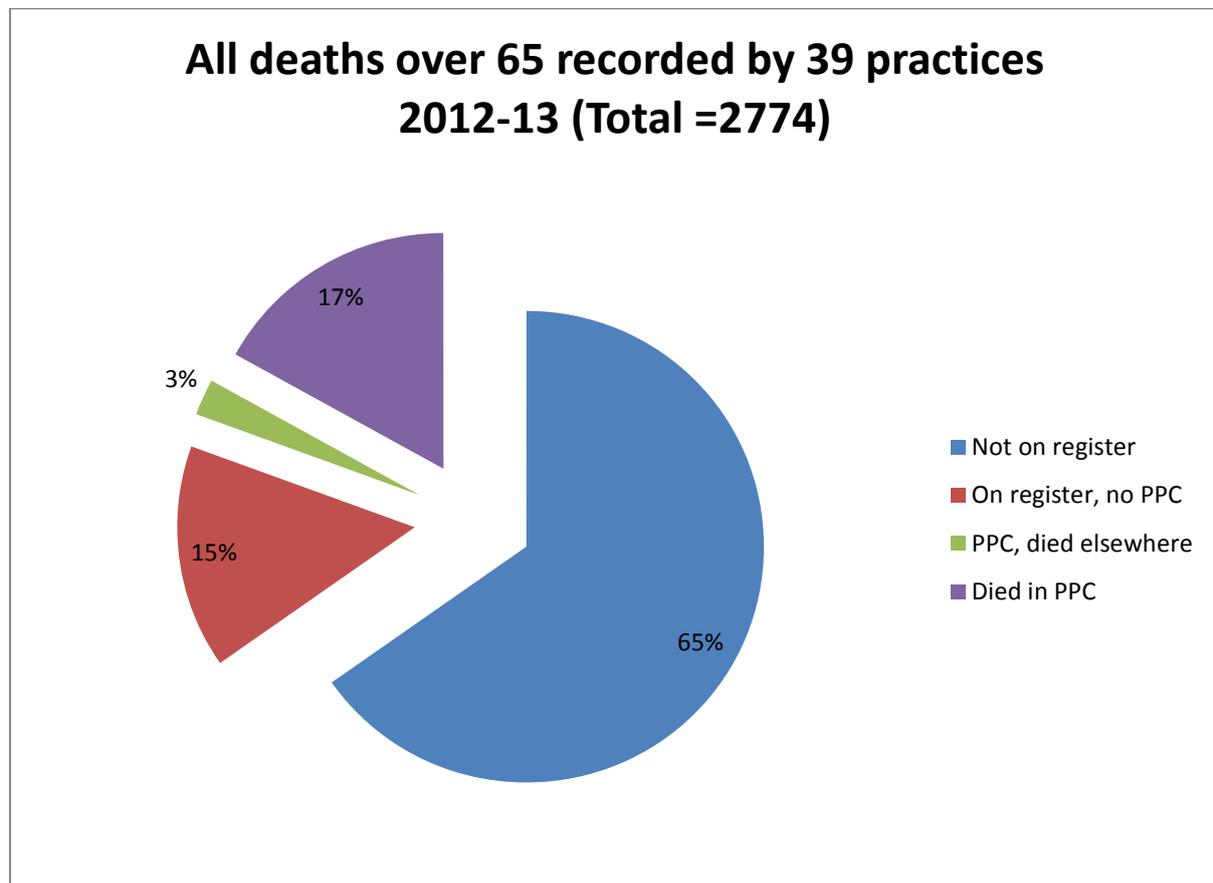
¹ End of life care strategy, Department of Health, July 2008

² End of Life care, UK National Audit Office Comptroller and Auditor General's report, 26 November 2008

³ Lessons from good practice: Kings Fund 28/10/10

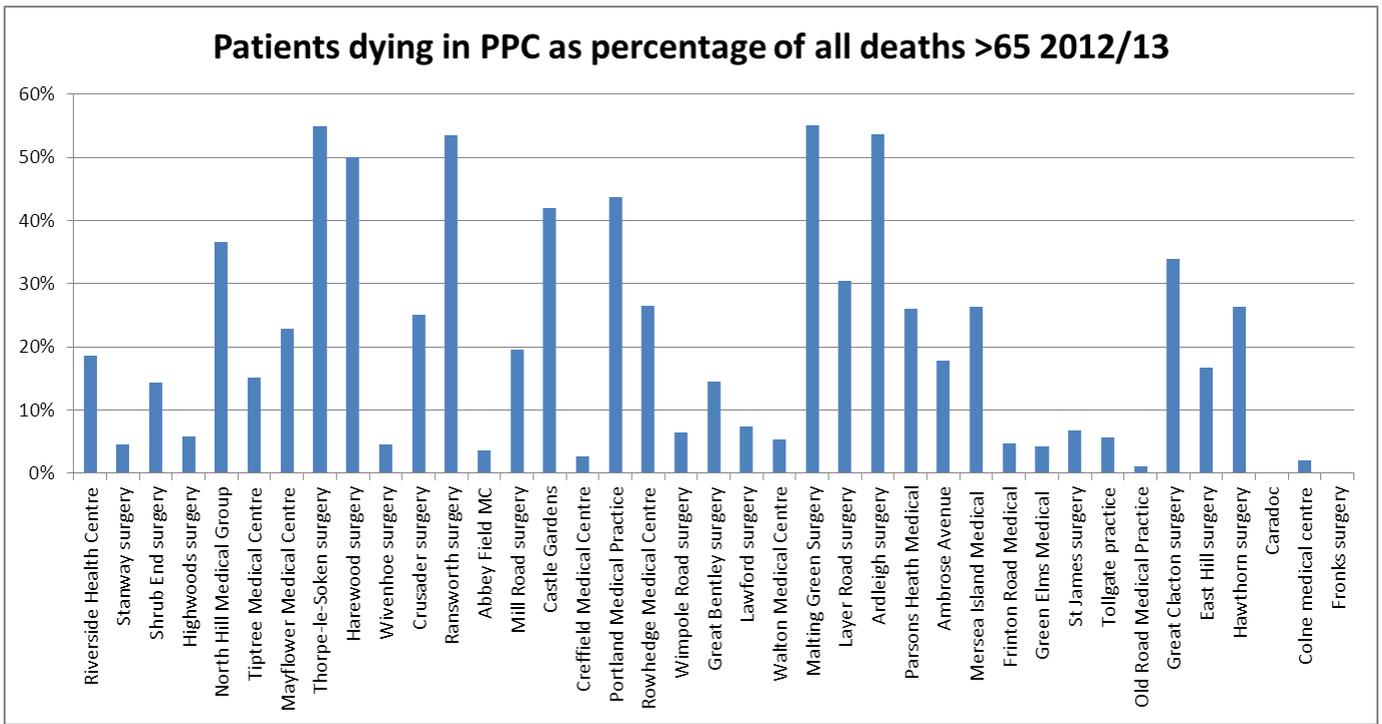
⁴ GP End of Life LES Baseline Audit Final Report - James Hickling August 2013

effective in meeting patient's wishes. The key areas that need to be addressed are the identification of more patients approaching the End of Life, and increasing the number who are offered choices about their care, including PPC.



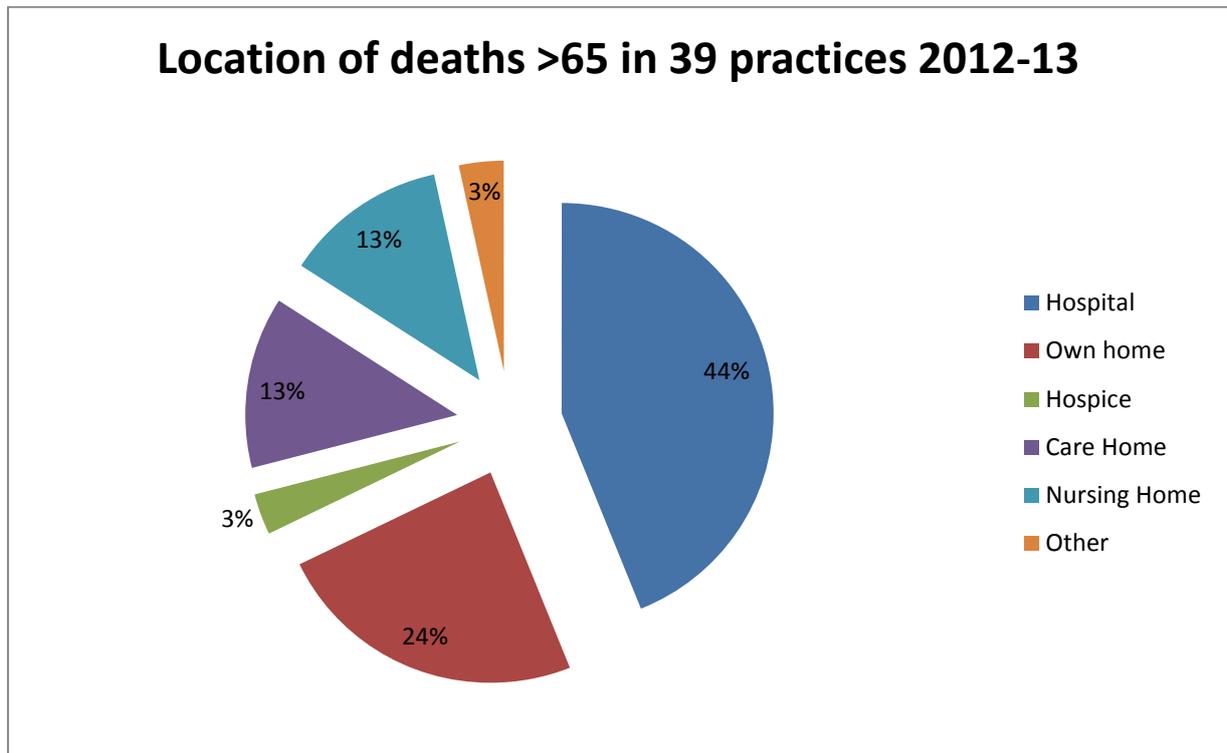
Deaths in PPC by Practice

There was a wide variation in performance between practices. Some practices were unable to extract the relevant data about PPC from their databases, and these have a 0% figure by default. There may also be data issues in some practices which could have overstated their performance. We expect the first data returns in October to provide a more accurate picture of the data as coding has been standardised.



Deaths by Location

The following chart shows where patients actually died.



This suggests that a significant number of those patients who were not on the register, or who had not chosen a PPC, still died outside of hospital. Many of these may have been in care homes and nursing homes where no formal End of Life plan existed, but where the clinical and care teams nevertheless recognised the End of Life status and cared for the individual appropriately. The hospital figures are consistent with the SUS data for deaths in hospitals.

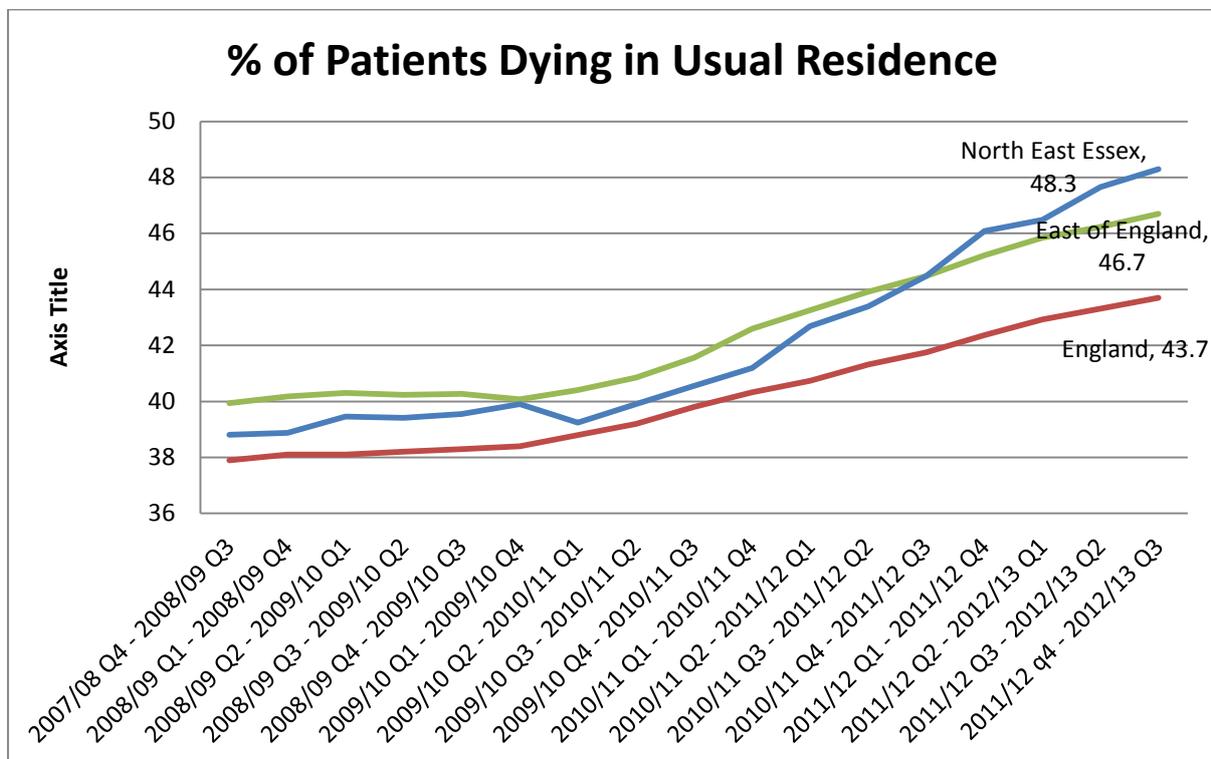
Local Enhanced Service: Key Outcomes

For 2013/14, practices have been set a target of identifying >50% of all deaths over 65 before death and adding them to their palliative care registers. Of these, they must discuss and agree a PPC, resuscitation status and add the patient to the online database in 80%. Of those stating a PPC, 50% or more should be able to die in their PPC. These are minimum standards. The LES provides additional incentives to practices for each patient who dies in their PPC and we expect many practices to exceed these targets significantly.

The first set of quarterly data under LES operation will be due by 31st October 2013.

The Office for National Statistics published figures in July 2013 which demonstrated that although the average life expectancy figures have improved over the last 3 years, the number of deaths in 2012 was higher than anticipated in particular the over 85 year age group. The figures demonstrate consecutive 3 year deterioration in the number of reported deaths in this age group.

This strategy will address the challenges identified by NHS Improving Quality, the Keogh Review and the impending challenges of an aging population and increased numbers of deaths predominantly in the over 65+ years with particular focus in the 85 years and over age band accompanied by the complexities of co-morbidity which often presents as a consequence of age. Commissioning will focus on ensuring equality of access and service provision across the Colchester and Tendring areas. The number of end of life patients in north east Essex dying in their usual place of residence compares well to the national and regional performance.



2 Vision and Objectives

The overall vision for end of life care in north east Essex, is that patients approaching the end of their life should be treated as individuals in relation to their emotional, physical and psychological needs, cared for with dignity and respect, be free from pain and other symptoms, in familiar surroundings in the company of close family and friends.

The strategic objectives in delivering this vision are in line with the NICE End of Life quality objectives⁵;

- People approaching the end of life and their families and carers are communicated with, and offered information, in an accessible and sensitive way in response to their needs and preferences.
- People approaching the end of life are offered spiritual and religious support appropriate to their needs and preferences.
- People approaching the end of life have their physical and specific psychological needs safely, effectively and appropriately met at any time of day or night, including access to medicines and equipment.
- People closely affected by a death are communicated with in a sensitive way and are offered immediate and ongoing bereavement, emotional and spiritual support appropriate to their needs and preferences.

Following the Bruce Keogh review of mortality rates at CHUFT in 2013, a risk summit proposed that the CCG and CHUFT, with other local stakeholders, agree a review of the End of Life Strategy locally by September 2013.

The original North East Essex Strategy was derived from the Marie Curie Delivering Choice Programme which reported in 2011 and was developed into workstreams through the End of Life locality group which have involvement of a patient representative. The review group⁶ found that significant progress toward implementing the key aspects of the strategy have been made; including introducing a 24 hour single point of access called "SinglePoint", extending the clinical response team's hours of operation to 8am-8pm as an interim measure, establishing an economy wide real time palliative care database and website "My Care Choices", however further work was required to address the findings both nationally by the NHS Improving Quality programme and locally by the Keogh Review. The end of life review group identified three specific objectives;

- To improve further the quality and experience of care for patients, carers and relatives
- To further reduce avoidable admissions to acute hospital
- To reduce the impact of End of Life admissions on SHMI

⁵ End of Life Care; Quality Standards (NICE 2011)

⁶ North East Essex CCG End of Life Strategy Review, August 2013

2.1 Commissioning High Level Outcomes

This end of life strategy outlines the required model of care and its multiple service elements to provide the high quality end of life support system that is based on national recommendation, best practice, local review outcomes and an entitlement for the patients of north east Essex.

The CCG will commission an integrated service model which will:-

- Provide consistently high quality and safe care 24/7 supporting patients and their carers' wishes
- Appropriate care is provided in the right place, by those with the right skills each and every time
- Is efficient in the delivery of care and services

A key component to the success of the strategy will be the integrated care planning approach that includes not just health care providers but also social care and voluntary sector. The framework for social care end of life⁷ states that *'Without the full engagement of social care in end of life care, the support provided for individuals and their families and communities as they approach the end of life will not achieve its full potential. Without recognition in social care services that many people may want to include end of life in their care planning, as well as a commitment to maintain quality of life throughout the end of life, the support that social care workers offer will similarly be less than it could be'*.

The Department of Health's End of Life Care Strategy and accompanying implementation programme is intended to change the 'culture' and experience of dying on three different levels: wider society's awareness, service user experience and the professional and service delivery infrastructure. The social care framework addresses the social care aspect of those changes. It signals a change in the way social care supports people at the end of life. The end of life model of care within this strategy therefore takes account of the vital role social care will play in caring for patients and their families.

Common key performance indicators have been agreed with our local providers Anglia Community Enterprise (ACE), Colchester Hospitals University Foundation NHS Trust (CHUFT) and St Helena Hospice in line with the GP LES to focus on outcomes that are patient-oriented: percentage of patients over 65 identified before death as nearing End of Life, the proportion offered full counselling and personalised Advance Care Plans (ACPs), and the proportion who die in their preferred place of care (PPC).

2.2 Operational Objectives

1. To deliver a stepped change in the coordination and timely provision of care to end of life patients towards a full 24/7 service model (Palliative Care Coordination Centre (PCCC), supported with the implementation of care co-ordinator/key-worker roles.
2. To actively identify more patients nearing End of Life and seek to capture their Preferred Place of Care (PPC) and create an Advance Care Plan (ACP)
3. To work with care homes to ensure staff are able to support residents nearing their end of life, thus reducing unnecessary emergency admissions
4. To ascertain the viability of providing community beds for End of Life patients in Tendring

⁷ Supporting People to Live and Die Well: a framework for social care at the end of life, Report of the Social Care Advisory group July 2010

5. To ascertain and close remaining gaps in training for specialist and generalist staff
6. To review effectiveness and quality of newly introduced services and identify gaps in care provision identified
7. To improve communication flows especially from secondary to primary care
8. To consider schemes to improve identification of patients nearing End of Life in acute hospital setting
9. To ensure that a local pathway is effectively implemented following the removal of the Liverpool Care Pathway
10. To ensure that the Amber Care Bundle approach is fully embedded within the acute provider organisation.

2.3 Patient Engagement

The North East Essex Clinical Commissioning Group as a lead commissioner for health services locally ensures that its address local health needs. Our values of Integrity, being person centred, inclusive and delivering improvement means that we cannot deliver our vision of “embracing better health for all” without the very people who use health services in North East Essex

In developing this strategy and understanding what is important to people we have set out to listen to people in a meaningful way that is neither “tokenistic” nor just simply “ticking a box”. Therefore we have set out to buy End of Life services that are as person centred as possible.

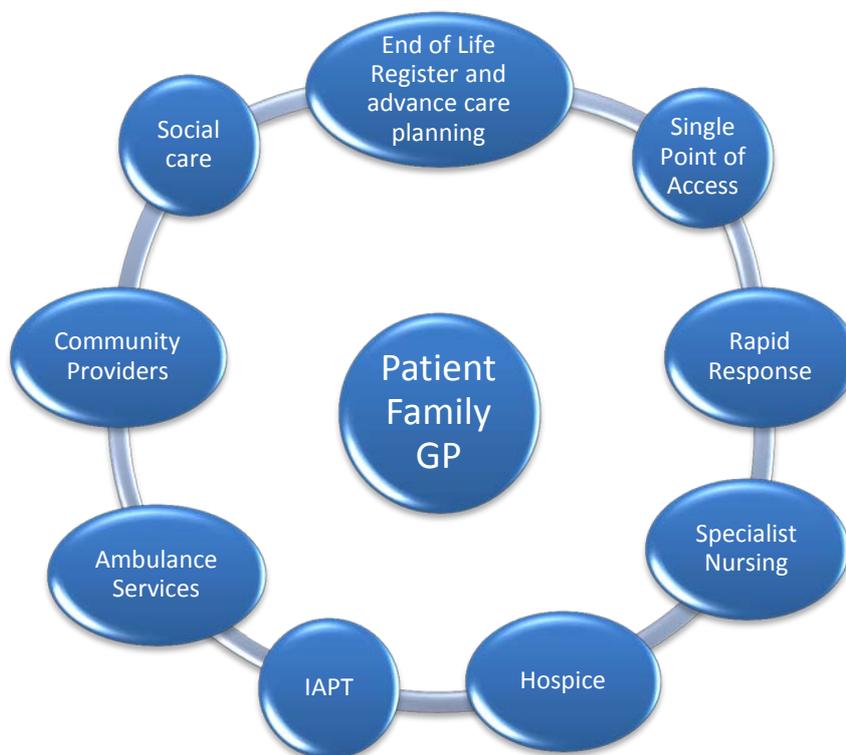
We have advertised for two services users to sit on the decision making board alongside side NHS staff to ensure we get out plan right. Also our CCG has undertaken a wider engagement exercise, ‘The Big Care Debate, which told us:

That people want choice about their health care options. For this reason we want to ensure that patient nearing the end of their life have the opportunity to agree preferred places of care

Communication is very important to patients and their families. This strategy looks to improve communication inside the NHS and with social care so people have a better experience and a say in services being developed and commissioned. They will also have a role in monitoring post award with feedback on services delivered.

3 The model of care

The end of life care pathway across north east Essex will be multi-faceted and will address all of the needs of patients and their families as they journey through the last year of life;



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Figure 1 Whole System Interdependencies for End of Life Care

- **GP** – the GP is the key medical professional in the provision of palliative care for patients in the community. The GP will be a key contact for patients and their families throughout the patient’s illness, providing support and advice in the management of symptoms and treatment options and explain the process of the end of life register, the advance care planning and the purpose of palliative team. The GP will work together with district nursing teams and communicating with the single point to provide coordination of care needs with other health care workers.
- **End of Life Register** - The electronic end of life care information system records the end of life preferences for patients who are nearing the end of life. GPs and specialist nurses will work with patients and their families to determine these preferences and gain consent to add this information to the care register. The use of advance care planning ensures that these decisions and any needs identified are then shared appropriately to help coordinate and provide the best care possible throughout the patients journey.
- **Single Point of Access** - A clinically led service made up of specialist palliative care nurses and community general nurses with knowledge and skills in palliative care who are able to expertly triage patients, offering advice and support when appropriate and plan individual care packages, including access to equipment. Administrative support will be crucial to the efficient running of the service. The centre will maintain the electronic End of Life Care Register. Health Care Professionals, patients and carers are able to directly access this service.

- Key-worker - The model of a 'key worker' to coordinate the care of people on end of life pathways will be developed and implemented. This will improve coordination of care and provide a much-needed single point of contact for carers.
- Rapid Response - the palliative care nursing team will be made up of nurses with the skills and knowledge in palliative care who are able to holistically assess, plan, implement and evaluate care to patients and families at home or care home. This service will include community nurses, nursing homes and care home staff in their generalist roles. In addition, advice to acute hospital staff will be provided as required, particularly out of hours. This service will also provide a rapid response element which will be available 24 hours a day, 7 days a week.
- Expert medical and rehabilitative care should also be available as a rapid service.
- Specialist Nursing - People approaching the end of life who may benefit from specialist palliative care, are offered this care in a timely way appropriate to their needs and preferences, at any time of day or night. Specialist palliative care encompasses hospice care (including inpatient hospice, day hospice, hospice at home) as well as a range of other specialist advice, support and care such as that provided by hospital palliative care teams. Specialist palliative care should be available on the basis of need, not diagnosis, the deciding factor often being for patients whose symptoms cannot be managed in a timely way by their usual care team.
- Hospice – Specialist medical services are provided and the Hospice care also exists to provide a type and philosophy of care that focuses on the physical, emotional and spiritual care for patients with life-limiting illness regardless of diagnosis. Care is offered as either inpatient, day care or domiciliary care and will include services able to support individuals complex needs as well as incorporating complementary therapies; chaplaincy, rehabilitation; counselling; social work; art and music therapy and bereavement support.
- Improving Access to Psychological Therapies - Psychological support encompasses general emotional support and empowerment as well as specialist psychological care. Specific psychological needs are more likely to require psychological interventions beyond the general emotional support that most people will need. Psychological interventions may include, but are not limited to, cognitive behaviour therapy, social skills training, work with phobias and confidence issues, and medication to ease psychological distress, including anxiety and depression.
- Ambulance Services – patient transport services will be commissioned to address the training needs within their organisation to provide a service that can access the end of life register to determine the most appropriate response for patients. Decision making skills based on criteria will help determine the most appropriate route; referral onward to the end of life single point of referral or convey the patient to an acute provider.
- Community providers - Qualified district nurses - 'specialist community practitioners in home nursing' - will have an appropriate level of education in palliative care. Social workers, occupational therapists, physiotherapists and other therapists will also have skills in palliative care.
- Acute Providers – the role of the acute provider is focussed on allowing and enabling natural death. Staff across all disciplines must have the skills to identify patients approaching their end of life and an awareness of their needs with the appropriate implementation of end of life care. Staff must have the skills to begin the advance care planning approach and communicate this with other care providers across the economy. There should be processes

in place to identify where advance care plans are already in place and fast tracking discharge where appropriate to achieve the patient's preferences. Organisational application of compliance with the national care of the dying patient pathway will be a prerequisite to successful commissioning.

- Social Care - Social care is underpinned by the human rights agenda and thus firmly allied to the Dignity Challenge agenda. Yet the general public is often unaware of the role that social care can play in improving people's experiences of dying, for example through access to domiciliary care services, acting as an intermediary with other services, and facilitating the making and upholding of individual choices. For some people there is also stigma attached to the involvement of social workers and cost implications for using social care services where health provision is free.

The Social Care Advisory Group produced; Supporting people to live and die well – a framework for social care at the end of life (July 2010). This framework provides 8 key messages to direct the role of social care in enhancing the end of life pathway;

1. Social care has a vital role to play in supporting people to live and die well, in the place of their choosing.
 2. The social care workforce – from domiciliary care workers to social workers and their managers - may need training and support to recognise the skills they have to facilitate this and to develop further skills.
 3. Social care services are undergoing a transformation in the ways in which they are conceived and delivered; social care at the end of life belongs to this agenda for change.
 4. Social work education and training are undergoing significant change, and training and skills development for the whole social care workforce is a government priority; education, training and support for the social care workforce in end of life care must be embedded in these wider changes.
 5. The personalisation and re-ablement agendas offer significant opportunities for improving the care that individuals and their families receive at the end of life. However, commissioning processes should also take account of the needs of people unable to take full advantage of these approaches.
 6. Palliative care social work is an educative and consultative resource for end of life care in mainstream services, as well as making a valuable contribution in specialist settings; strengthening this service offers considerable potential for increasing social care capacity in end of life care.
 7. Greater integration is needed across all care and support services, particularly social and health care, to improve the experience of dying for the individual and those around them. This includes tapping potential in the wider community (and other public services) to enhance quality of life at this stage.
 8. There needs to be a robust evidence base to support the development of good social care practice in end of life care.
- Care after death, bereavement support - people closely affected by a death should be able to access all support within an appropriate physical environment that facilitates sensitive communication⁸. Families and friends (including other residents and patients), carers (including health and social care providers) of people who have died should have access to information and support appropriate to their circumstances. Children may need particular tailored support.

⁸ End of Life Care; Quality Standards (NICE 2011)

The department of Health 2005 bereavement guidance⁹ recommends that bereaved people are offered support at the time of death that is culturally and spiritually appropriate, immediate, and available shortly afterwards, but not limited to the initial period.

Bereavement support should include at a minimum;

- Information about local support services practical support such as advice on arranging a funeral, information on who to inform of a death, help with contacting other family members and information on what to do with equipment and medication
- General emotional and bereavement support, such as supportive conversations with generalist health and social care workers or support from the voluntary,
- Community and faith sectors referral to more specialist support from trained bereavement counsellors or mental health workers.

Specific care tools for end of life care have been developed and rolled out nationally and these must be incorporated as best practice ways of working for the integrated approach to end of life care across all disciplines and across the north east Essex health economy;

- Gold standard framework (GSF) – provides community health care teams with tools to improve the planning of palliative care by ensuring that end of life patients are identified, their needs are assessed and high quality care plans are put in place to address these needs. The GSF, when applied appropriately, makes sure that no element of a patients care needs is ignored or forgotten.
- Liverpool care pathway (LCP) – In a report by the independent review of the LCP, the panel called for a coalition of regulatory and professional bodies to lead the way in creating and delivering knowledge base, education, training, skills and the long-term commitment needed to achieve a revised end of life care plan. Organisational compliance with the national recommendations in high quality individualised care plans for care of the dying patient will be a prerequisite to successful commissioning.
- Advance care planning (ACP) - is a voluntary process of discussion about future care between an individual and their care providers, irrespective of discipline. If the individual wishes, their family and friends may be included. It is recommended that with the individual's agreement this discussion is documented, regularly reviewed, and communicated to key persons involved in their care. An Essex wide ACP has been developed through consultation with primary, secondary and independent care providers and commissioners. The CCG expectation is that this will be fully utilised by provider organisations to ensure a holistic approach to joint care planning to ensure that people die well.

3.1 End of life care for people with dementia

People with dementia who are dying should have the same access to end of life care services as those without dementia.

NICE commissioning guidance¹⁰ for end of life care for people with dementia identifies the main benefits of effective commissioning end of life pathways for people with dementia;

⁹ When a patient dies: guidance for professionals on developing bereavement services (DoH 2005)

- reducing inequalities and stigma by improving access to information, advice and a range of supportive services
- improving the psychological, physical and spiritual well-being of people with dementia and their carers through access to an appropriately trained workforce
- improving the quality of care through timely interventions in the right place by a knowledgeable and caring workforce
- increasing choice through advance care planning, advance statements and Advanced Decisions to Refuse Treatment (ADRTs)
- reducing unnecessary hospital admissions by developing capacity to deliver expertise to the patient's home and through more effective use of technology and workforce development
- improving cross boundary and partnership working, improving care coordination, minimising unnecessary duplication and reducing costs
- reviewing the use of continuing care funding and the support available for people with dementia
- supporting carers and ensuring access to an assessment of need as set out in the Carers and Disabled Children Act 2000 and the Carers (Equal Opportunities) Act 2004
- improving knowledge and skills in specialist and generalist dementia and palliative care settings, and in independent residential and nursing homes
- better value for money through the use of cost-effective interventions which span pharmaceutical, psychological and social support, including support for daily living/equipment and transport.

However the challenges faced in relation to treatment planning and communication differ for people with dementia in that the decline in health is less predictable and more variable, making prognosis difficult. The deterioration in communication skills prevents people with dementia from expressing their views and wishes later in the disease pathway.

In determining the capacity requirement for end of life care for patients with dementia, NICE drew comparators with the prevalence of dementia and the total number of deaths. Available data suggest that the indicative benchmark for the number of people with dementia who require end of life care is around 800 per 100,000 people, aged 65 and older, per year. The 65+ years population for north east Essex is 71,557, therefore this equates to 572 patients per year. This figure will vary dependant on the local demographics which is known to have a higher than average elderly population as well as the problems of undiagnosed dementia. The prevalence of dementia increases with age and given the increase in life expectancy, the number of patients presenting with dementia will increase and as a direct consequence the number of dementia patients requiring end of life care will also increase.

Implementation of the Alzheimer Society recommendations for improving end of life care for people with dementia, will be embedded within the performance framework of the commissioning intentions to ensure these issues are addressed across the health and social care economy;

¹⁰ *End of life care for people with dementia: commissioning guide NICE 2010*

- Improve recording of the presence of dementia on death certificates, to enable more accurate data collection and an understanding of the level of need.
- Support the use of clinical indicator checklists (eg the checklist contained in the Gold Standards Framework) to identify those patients who would benefit from a palliative care approach in all care settings.
- Ensure protocols that guide staff on the end of life care of people with dementia are implemented. Among other things, these protocols should include:
 - the importance of allowing adequate time to understanding the particular needs of the person with dementia,
 - detecting and treating pain in people with dementia
 - understanding the person's spiritual needs.
- Only staff specifically trained to do so and who are judged to be effective communicators should ask carers for their views on decisions around potentially life sustaining treatment.
- Involving carers in treatment decisions is vital, however their views can be different to that of the person with dementia, therefore the independent mental capacity advocacy service should be expanded to all decisions around end of life treatment where there is no advanced decision to guide clinicians.
- Dementia care should be a core part of all nurse training and continuing professional development, particularly to improve the care of people with dementia in hospital.
- In order to improve hospital care for people with dementia, liaison psychiatry services for older people should be supported and expanded, as outlined in 'Who cares wins' (Royal College of Psychiatrists, 2005).
- Liaison and outreach between specialists in dementia care and in palliative care should be developed to share knowledge and skills between the two areas.
- The model of a 'key worker' to coordinate the care of people in the final stages of dementia should be developed and evaluated. This would improve coordination of care and provide a much-needed single point of contact for carers.

4 Workforce Planning

This strategy identifies the model of care to be commissioned as well as the best practice tools to be implemented in the care of end of life patients and their families and carers. To achieve this we need a well-trained and supported workforce, operating in the right kind of commissioning and assessment environment and unconstrained by the traditional boundaries between health and social care.

NICE provide guidance on workforce training requirements in relation to the end of life service, which will be considered as a qualifying factor of the procurement process and detailed within the service specification. Broadly these recommendations are:

- Curriculum content relating to end of life care contained within pre-registration and undergraduate education for health and social care.
- Training programmes within hospitals, community settings, care homes, ambulance services and other health and social care settings including end of life training.
- Taking into account communication skills (including issues around loss, grief and bereavement), spiritual care, assessment and care planning, advance care planning and symptom management as they apply to end of life care. Also training related to the Liverpool Care Pathway for the dying patient (LCP) or equivalent integrated care pathway.
- Particular account should be taken of the training needs of those workers involved in discussing end of life issues with patients, families and carers. Talking about end of life care: right conversations, right people, right time from the National End of Life Care Programme provides information on communication skills training.
- Specialist palliative care services to act as an educational resource for training generalist palliative care in the community, including GP practices, district nursing services, care homes and community hospitals, and acute hospitals and other services.
- Medical and district/community nursing out-of-hours workers should be competent in providing general palliative care, including symptom management, the use of syringe drivers, assessment of need, communication skills and providing support both to the patient and to carers in relation to 'do not attempt cardiopulmonary resuscitation' orders (also 'do not attempt resuscitation' orders), and advance decisions.

Training plans should include;

- The use of End of Life Care for All (e-ELCA) (e-learning resource commissioned by Department of Health) in conjunction with face to face teaching, work-based learning and peer education.
- The AMBER care bundle; a simple approach used in hospitals when clinicians are uncertain whether a patient may recover and are concerned that they may only have a few months left to live. It encourages staff, patients and families to continue with treatment in the hope of a recovery; while talking openly about people's wishes and putting plans in place should the worst happen. The four main elements of the care bundle are :
 - talking to the person and their family to let them know that the healthcare team has concerns about their condition, and to establish their preferences and wishes
 - deciding together how the person will be cared for should their condition get worse
 - documenting a medical plan
 - agreeing these plans with all of the clinical team looking after the person.

The AMBER care bundle contributes to people being treated with dignity and respect and enables them to receive consistent information from their healthcare team. It helps people and their carers to be fully involved in making decisions and knowing what is happening with their care.

- Further training and development will be required to address end of life care in prison and hostels.

Provider organisations must also address the spiritual needs of end of life patients and provide staff with the appropriate knowledge and experience for example; Marie Curie Cancer Care spiritual and religious care competencies for specialist palliative care which outlines four different competency levels for staff working in all areas of care, both specialist and non-specialist.

Local Education and Training Boards (LETBs) will work collaboratively with providers to deliver effective workforce planning. To this end they have identified local transformation priorities which have particular relevance to the end of life pathway;

- **NHS Constitution values and behaviours** - to ensure East of England (EoE) delivers the highest quality patient and service user care through raising awareness of the NHS Constitution, reflecting this in our recruitment and working with our partner employees to ensure these values are reflected in ALL of our staff
- **High quality care for the frail elderly (including those with dementia)** – improving the quality of care, reducing acute admissions and embedding a patient centred approach through integrated roles, training and leadership, developing the community and primary care workforce, balancing the need for diagnosis and treatment with the need for care and compassion and embracing technology to support self care and mobile working
- **Improving urgent and emergency care services and reducing avoidable admissions and preventing unnecessary hospital stays** – enabling integrated care pathways and the development of community based services

The CCG will commission specialist palliative care teams based on the NICE cancer service guidance¹¹ recommendations, to include:

- palliative medicine consultants
- palliative care nurse specialists
- a team secretary/administrator.
- a range of expertise provided by ALIED health professionals
- social workers
- chaplains/spiritual care givers
- professionals able to deliver psychological support equivalent to level 3 of the psychological support service model (see topic 5, psychological support services).

¹¹ *End of Life Care; Quality Standards (NICE 2011)*

5 High quality, patient centred care

The National Confidential Enquiry into Patient Outcomes and deaths (NCEPOD) 2009 looked at patients who had died within 4 days of admission and the challenges faced by provider organisations to move from a single purpose of saving life to allowing natural death. The report identified the need for organisations to address the lack of skill in identifying patients approaching their end of life, lack of awareness by staff of the needs of patients nearing the end of their life, inadequate implementation of end of life care and the inability to communicate with patients, relatives and other care providers.

Despite the identification of these issues in 2009, the Keogh Review identified that little had been done locally to address these issues.

As part of the commissioning round the CCG will introduce a quality assurance programme based on the quality markers within the national End of Life Strategy (2008) to ensure that the gold standard framework is being achieved. These will be detailed in the service specification and reporting mechanisms will be in place to ensure compliance.

End of Life Quality Markers

1	Have an action plan for the delivery of high quality end of life care, which encompasses patients with all diagnoses, and is reviewed for impact and progress.
2	Institute effective mechanisms to identify those who are approaching the end of life.
3	Ensure that people approaching the end of life are offered a care plan.
4	Ensure that individuals' preferences and choices, when they wish to express them, are documented and communicated to appropriate professionals.
5	Ensure that the needs of carers are appropriately assessed and recorded through a carer's assessment.
6	Have mechanisms in place to ensure that care for individuals is co-ordinated across organisational boundaries 24/7.
7	Have essential services available and accessible 24/7 to all those approaching the end of life who need them.
8	Be aware of end of life care training opportunities and enable relevant workers to access or attend appropriate programmes dependent on their needs.
9	Adopt a standardised approach (the Liverpool Care Pathway or equivalent) to care for people in the last days of life.
10	Monitor the quality and outputs of end of life care and submit relevant information for local and national audits using a locally determined dashboard

5.1 High level risks

As with all service change some risks have been identified;

- IG and IT issues prevent health professionals accessing relevant patient data
- People do not change behaviours
- Growing aging population demand and reduced funding
- Market place is not sufficiently mature and developed to be able to work in full integration and meet demand of PPC
- Impact of Keogh on public confidence in local services
- Impact of Keogh on clinical risk thresholds

Each risk will require the development of a mitigating action plan and assurance to the End of Life Project Board.

6 Finance

As a health economy, commissioners and provider organisations have worked jointly to provide care closer to home for end of life patients. The model of care in the community should drive financial efficiencies through the reduction in emergency admissions and streamlined service provision.

Although developments have been put in place in line with the national strategy recommendations, the data produced by NICE, NHS Improving Quality and Kings Fund identifies that further work needs to be done to achieve the objectives of the strategy. This was confirmed locally by the Keogh Review that identified that the number of end of life patients who die in hospital remains high.

The delivery of this end of life model of care will bring about the efficiencies identified in the NICE Commissioning Guidance¹² through the appropriate provision of community support to end of life patients and their families and carers through;

- the reduction in emergency attendances
- reduction in duplication of services

The CCG will identify financial incentives (CQUIN) to support the increase in the number of patients managed on the Gold Standards Framework within north east Essex by identifying more end of life and palliative patients within the acute setting, initiating discussions with them and their families, and ensuring more effective communication via discharge summaries to GPs. The measure of this CQUIN will be;

- Increase the proportion of the patients identified at discharge that are on an end of life pathway and included in the discharge summary to support GPs placing patients on the GSF register.
- 90% of patients discharged on the fast track (rapidly deteriorating pathway) or under the care of the Specialist Palliative care team to have end of life status and confirmation as appropriately discussed with patient / carer included on discharge summary by Q4 2013/14

7 Procurement

Much of the development work for 2012/13 and 2013/14 has worked towards delivering the model of care outlined within this strategy as the preferred service model. This work has been funded through a combination of local enhanced schemes (LES payments) and transformation funding which will continue until the end of the financial year 2013/14. This will provide a 6 month testing period to gain an understanding of what works well and what could be improved. The outcomes of the testing period will be incorporated into the model and appropriate amendments made. An interim review will be taken by the end of December 2013 by the End of Life Board to determine progress against Keogh recommendations. Funding mechanisms will need to be identified and agreed for 2014 - 2018. The service will then follow the appropriate procurement process.

¹² Guide for Commissioners on End of Life care for Adults NICE 2011

8 Delivery

This strategy is a five year commissioning programme with the initial focus on resolving the issues identified in the Keogh Review and will be implemented by the North East Essex End of Life Programme Board and supported by Urgent Care and Care Closer to Home Bundles Commissioning Strategies. This Group will report to North East Essex CCG Programme Board. The high level timetable and milestones can be located in Appendix 2. This will be reviewed and updated as plans progress.

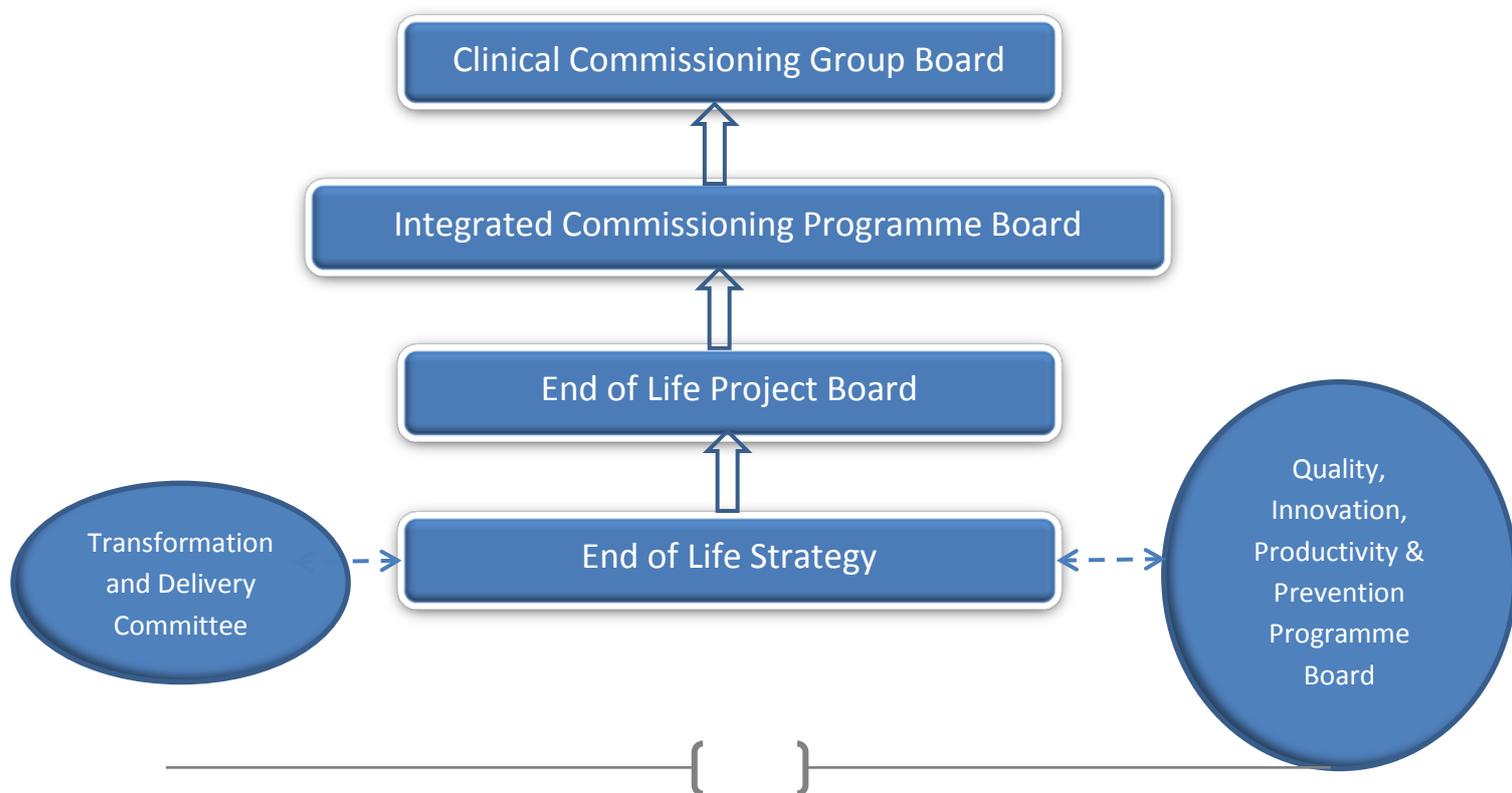
9 Programme Governance

The CCG governing body and its sub-committees have all adopted the key principles of:

- Clinical Commissioning must be focused on individual needs and promote the health and wellbeing of communities, as well as addressing health inequalities.
- Clinical Commissioning must work in the spirit of public service, professionalism and selflessness to serve our local population.
- Clinical Commissioning should be driven by the health needs of the population, prioritising our commissioning towards work which delivers the greatest improvements in health and the best possible experience for all.
- Clinical Commissioning will seek to continually improve quality wherever possible and to embrace innovation to achieve this, within available resources and ensuring value for money.
- Clinical Commissioning must be drivers of strong clinical leadership and enablers of clinical empowerment.

This strategy has been developed based on these commissioning principles and the internal rigor in the authorisation of this strategy is outlined in figure 2 below;

Figure 2 NEE CCG Programme Governance



Appendix 1 End of Life Implementation Plan

Ref	Objectives	Quality Requirements	Lead organisation
1	Integrate and improve community End of Life services	Single shared database Single point of access 24 hour rapid response Documents follow patients Improved communication between primary and secondary care, especially at discharge Intermediate care integration within locality teams End of Life team integrated into locality teams Training key nurses as end of life assessors	St Helena's Hospice CHUFT ACE St Helena's Hospice St Helena's Hospice
2	Improve primary care management of End of Life	Identify patients early Establish and record patient choices: PPC, DNACPR Effective palliative care review meetings – anticipatory prescribing, entry on shared database, notification Refer appropriately Going for Gold	GP LES CHUFT GP All All
3	Improved Bereavement Care	Offer bereavement support to all bereaved people in NEE, including homeless people.	St Helena's Hospice
4	Improved patient and carer feedback and involvement	Patient/Family/Carers feedback survey by all providers on-going. Quarterly publishing of survey outcomes	St Helena's Hospice
5	Improved access to medication and equipment Improved understanding of medication by patients / carers	24hr pharmacy access and improved medicines management processes to focus on reducing delays	CCG
6	Education of NHS and social care workforce	Continuous education of carers Hospital staff education programme GP education course Advanced communication skills	ACE CHUFT St Helena's Hospice All



7	Integration with 111	Ensure recognition of patients as EoL	CCG
8		<p>Introduce KPIs aligned with patient outcomes</p> <p>Update training for EoL team in database and SPoA</p> <p>Review training and effectiveness of COPD and Heart Failure teams in EoL care</p> <p>Ensure EoL team accredited to sign DNACPR</p> <p>Embed extended hours into contract</p>	ACE
9		<p>Introduce KPIs aligned with patient outcomes</p> <p>Monitor effectiveness of 24/7 SPoA and triage, establish any gaps</p> <p>Embed 24/7 working into contract</p>	St Helena Hospice
10		<p>Roll out telephone pilot of EoL concerns to all depts.</p> <p>Agree format for EDS communication in definite EoL Cases (re CQUIN), 24hr discharge summary target to approach 100%</p> <p>DNACPR forms to follow patients covered by CQUIN</p> <p>Agreed communication form in other cases</p> <p>Adopt replacement for LCP and extend training to all departments</p> <p>Implement Amber Care Bundle across organisation</p> <p>Explore effective ways of embedding EoL screening, case finding and ACP discussion into routine practice</p>	CHUFT

Appendix 2

8. High level timetable and milestones

Milestone	Implementation
2% bid for Palliative Care Coordination Centre (PCCC) (Single Point of Access) project commences	May 2013
GP End of Life LES commences – Audit and benchmarking data	July 2013
Review of Community Beds commences (possible End of life use as an option)	Aug 2013
SinglePoint telephone line commences	Sep 2013
Extended hours in End of life community and hospice services (12h/7d)	Sep 2013
End of life rapid response services extended to 24/7	Dec 2013
Interim review of new services commences for capacity demand, effectiveness and quality	Jan 2014
Decision required on extending LES to March 2015 to facilitate procurement process during 2014/15	Jan 2014
Final review of the service and financial outcomes of existing programmes against 2% bid	May 2014
Reconfigured community beds in operation	April 2014
Procurement Options Appraisal and/or Partnership Working to be scoped for NEE End of life services	Jan-April 2014
Decision on End of Life Service delivery future model	May 2014

